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EDITORIALS

Avoiding premature death in epilepsy

General practice is the place to start, and much can be done

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An estimated 1.16 per 1000 people with epilepsy die suddenly each year.¹ In 2013 there were 680 deaths from epilepsy among people aged under 75 (973 deaths at all ages) in England and Wales.² Sudden death in epilepsy peaks in young adults, particularly men, so a 20 year old with epilepsy has a greater than 1% risk of dying before he reaches 30, before adding other known risks for sudden death. Comparing years of potential life lost from neurological disease, epilepsy is second only to stroke.¹ Research on this topic has focused on cohort studies¹ and whether risk should be explained to patients.³ However, equally important and currently unanswered questions are: can group and individual risks for death be identified, perhaps using patients' routine electronic records? Are some identified risks amenable to better medical management? And will cash strapped governments pay for it?

Some deaths are unavoidable, but improved care might result in fewer unnecessary, untimely deaths. General practitioners routinely identify risks of heart disease and stroke in the UK using electronic records and discuss them with patients. National strategy also supports risk identification for cancer in primary care.⁴

With others, I conducted a pilot study that showed it was feasible to identify specific risk factors for death in epilepsy, which had been derived from cohort studies, using routine data from GPs' electronic records.⁵ We found that people with epilepsy and alcohol problems had an almost threefold increased risk of death. The risk in patients who had not collected their most recent anticonvulsant prescription in the past three to six months was nearly doubled. Having "a history of injury" during the previous year increased risk by 40%, and having had treatment for depression increased risk by about the same.⁵

A European collaboration, AMIEHS (Avoidable Mortality in the European Union: Towards Better Indicators for the Effectiveness of Health Systems), has set up criteria to identify causes of avoidable death and to compare outcomes across Europe.⁶ Inclusion criteria for putative conditions are that death rates must be over 100 a year and must have declined somewhere by at least 30%.⁶ Cervical cancer and Parkinson's disease have already been included. Death rates from Parkinson's disease have fallen by 30%, but because the onset

of Parkinson's disease is usually at an older age, many fewer potential years of life are lost. The challenge is to develop and evaluate interventions that reduce epilepsy mortality by at least 30%.

Identification of risk

Everyone with epilepsy has to be assessed in order to capture those most at risk. In some Nordic countries, specialists provide continuing care for people with epilepsy and have electronic records.⁷ They can identify population, and potentially individual, risks. An English study found that 20% of people with epilepsy who died suddenly had been in contact with specialist services in the previous year.⁸ About 90% of deaths occurred in people with tonic-clonic seizures that had increased in frequency in the previous three to six months. One half had a record of alcohol misuse, and a quarter had been taking drugs to treat depression or anxiety.⁸

Virtually every person in the United Kingdom is registered with a GP. From 2004-14 GPs were remunerated for keeping a register of people with epilepsy using their electronic records and for reporting if patients were seizure-free. GPs also stored more detailed information on the other risks that could affect outcomes. What could researchers do to help GPs identify those at higher risk of death in epilepsy? An in-depth analysis of electronic records from 2004-14 would produce more precise risk estimates. Risk assessment tools, which have already been developed for other conditions presenting in primary care,⁴ could evaluate individual symptoms and signs and visually present combined risks, alerting GPs to "red flag" profiles. Such tools should be developed and piloted for people with epilepsy, with input from users.

What could GPs do as risk managers? As in other conditions, individual risks differ and require specifically tailored step-up care. GPs could monitor, manage, and, where necessary, refer patients to community or secondary care teams. Patients who do not collect their prescription could be automatically identified and contacted directly, with reminders in primary care. Patients with substance misuse can be referred to local addiction services. In a cohort study, 30% of deaths were unintentional, mostly from drowning and burns.⁹ People with an injury linked to a

seizure may present in primary care or in the emergency department. This could trigger referral to an epilepsy nurse specialist for advice on self management of risk.¹⁰

Death in epilepsy is associated with depression.⁷ A community study found that people with epilepsy who report symptoms of depression subsequently report poorer seizure control and that this relation is bi-directional.¹¹ Depressed people with epilepsy are also less likely to adhere to their medications.¹² A vicious cycle of prior risks seems likely to accumulate, with seizures leading to depression, depression leading to less effective medication self management, more frequent seizures, and a cumulative risk of death. A risk assessment tool which added the positive predictive values of each risk would alert GPs. Screening for depression is good practice in several long term conditions. This should include epilepsy. Antidepressants and cognitive behavioural therapy might reduce depression and improve self management and could be tested in a trial.

This may seem a tall order. But up until 1988 GPs did not call and recall people to check for the risk of cervical cancer. Women who died had often never been checked.¹³ Since monitoring began annual death rates have more than halved,¹³ and there are now fewer deaths than the number for epilepsy.² The NHS estimates it spends £175m (€235m; \$268m) a year on identifying people at risk from cervical cancer, referral for closer monitoring, and, if necessary, for surgical intervention.¹³ General practice is not the only place that the risk of death in epilepsy can be identified in the UK, but since most of the risks are non-neurological it is the right place to start.

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